Raisa Habersham 0:07

Welcome to Hidden Voices, I'm your host Raisa Habersham. Join me on my journey to learn more about the experiences of Georgia residents with developmental disabilities guided along the way by my co-host and mentor, Derona King.

Learning about people with developmental disabilities is a fairly new world for me, as it may also be for some people listening to this podcast. So when the team behind Hidden Voices contacted me about going on a journey to learn more about the lives of people with developmental disabilities, I was excited. But I was also nervous. I'm a journalist who has spent the last four years writing about the diverse experiences of people who live and work in the city of Atlanta. I'm a storyteller to my core, and I consider it an honor to be entrusted with sharing a look into someone else's life. But at the same time, this assignment came with some heavy questions. Am I being fair and accurate? How is this being framed? Will I do their stories justice? The answer to all three questions is the same. I'm here to do and be my best. I've learned it takes courage to venture into the unknown, to learn about life experiences that seem so different from your own, to be prepared, to get it wrong. My hope is that through this journey of asking difficult questions and facing difficult truths, I become more aware of the challenges people with disabilities face and become a better advocate in the process. This season of Hidden Voices will follow me as I learn about the effect isolation has on Georgia residents with developmental disabilities. With the pandemic, isolation is now at the heart of conversations worldwide. And the isolation experienced year after year for people with developmental disabilities can become tenfold in a global crisis. We'll hear how people are navigating love and family in a world more isolated than ever. We'll also hear how people with developmental disabilities are leaning deeper into their faith amid isolation. In this episode, we'll learn about citizen advocacy and how through it, people can advocate for themselves and others. We'll also hear how one person citizen advocate has become like family, I'll be guided along the way by the Derona King, who is the executive director of Citizen Advocacy of Atlanta and Dekalb. Derona has been with citizen advocacy for 27 years, I wanted to know more about why she became involved with citizen advocacy. Apparently, she had an eye opening job experience.

Derona King 3:11

So, back in the early '90s, I was involved with just a small nonprofit. And we got data on – essentially on what people were paid. And that job showed me that in our country, in our nation, in our state, in our city, it is acceptable to pay people with disabilities sub-minimum wage.

Raisa Habersham 3:32

Oh my goodness.

Derona King 3:33

It arrested me to think that anybody, whatever kind of job it was, that someone would get a paycheck for $0.25, or $0.10, or $1.37. And I can remember asking my boss And I can remember asking my boss, like, "What is this? And how is it possible?" And she's saying, "That's really what they're getting paid for this work." And I remember saying, "The paper that that check is written on is worth more than this person, whoever this person is, is being paid. How can that be, anywhere in the United States, be the case?" And so what I learned very quickly is that we have these what's okay for the general population rules, and then what's okay for people with disabilities?.

Raisa Habersham 4:10

Oh, my goodness, that's horrible.

Derona King 4:12

And we have again, as I talked about this hidden and blind world, we have no idea as a society that we contribute to this.

Raisa Habersham 4:22

Citizen Advocacy helps create advocacy relationships between people with developmental disabilities and people who may or may not have one. Derona’s role is to ‘match’ these relationships and support those who are advocating for themselves and for others.

Derona King 4:37

I encountered someone who became a lifelong friend at this point, who began to talk to me about something I'd never heard of like this, this notion of how important it is for people to have valued social roles, and how people with disabilities are often kept from having, almost intentionally, kept from having valued social roles, but live their lives for decades, as clients of a system. And once you become seen or viewed as just a client of the system, you no longer have control, the system has control. And that shows up and things like how much your, how much money, you might get Medicaid, you know, what we vote on for tax dollars, how buildings are built, or not built for accessibility, and whether people get to have real homes of their own, or meaningful things to do with their days, or personal relationships. So I began hearing this from this friend who literally said to me, have you ever heard of Citizen Advocacy and like, I had not. And I took it upon myself to call and what I heard about Citizen Advocacy resonated with how I perceive how I want to walk through this world of valuing people and bringing dignity to people's lives. The point is that you lift up what people have more in common than what they have, that that people seem to distinguish people by when people begin to identify and see that they have more in common with someone than someone else. They're apt to act on that person's behalf. So it's less about people having some formalized way to speak up or ally, not that that's a bad thing. But it's more about in regular community, that we recognize our neighbors as human beings. And we are able to recognize that even though there are differences or distinctions that may seem on the outside, that inside, we all need the same thing. We need interaction, we need love, we can compassion, you know, we need companionship, those are the real important things. Those aren't the things that can be legislated. Those are the things that human beings bring to one another.

Raisa Habersham 7:00

How has working at Citizen Advocacy and you know, being a coordinator now director changed you as a person?

Derona King 7:08

I think this work that I do has helped me to be more curious about people and less certain about things. Being curious means that I'm not going to take somebody else's word about what they say about you, Raisa. I'm going to take the time to get to know and share with you myself, and lay down whatever assumptions, I've really been cognizant of the assumptions that come along with being certain about something right. You're so certain and set, that I think that's really important when it comes to appreciating people from different backgrounds and situations that we lay down some of those assumptions and certainties. And we begin to be more curious.

Raisa Habersham 7:54

I tell Derona that I really connected with the housing and transportation episode from season one. As a child growing up in Atlanta, I had my challenges with both these issues had a way of distinguishing the haves and the have nots. And I know personally how isolating it can feel to be a have not. And that isolation can feel just as lonely in a pandemic, when you can't touch or see the people you love. I'm an introvert. So being at home alone and away from people doesn't bother me. But the truth is, I have the choice to be alone when it's most comfortable. And even then, I'm not completely alone. I live with my husband who teaches in a school district where many of the students have economic challenges. And so it's heartbreaking just to know some of the stories that I hear that come out of my husband's classroom, he had one parent who had to email him and let him know, hey, you know, I know my son's been absent from class, it's because I just recently got a job, and I'm trying to save up to buy him a laptop. And you know, things like that are heartbreaking, because it feels as if you can't do anything about it. And so for a lot of the students, especially in the county that he works in, they have immense isolation.

Derona King 9:16

Isolation is huge for people. And in our conversations of considering this particular moment in time and in our history, almost juxtaposed against the common experience of people with disabilities, we only are getting a small glimpse of this. People who are often isolated because of disability, that's normally hard. That's typically very hard, have gone from this typical separation and segregation of the general population, to even now being segregated and isolated by themselves. So an example might be someone who, before the pandemic, lived in a group home with other people who have disability, so they're already in a segregated environment. They're not just kind of living and moving and breathing in the ways that the typical population with, their world is segregated, disability world. So that group home of six people, because of the pandemic has now been pared down two to three people who may even be separated in their own rooms throughout the course of any given day. Just what our experience for most of us is living in this disembodied Zoom world has an impact on us. For people with disabilities, there are very few opportunities for them to even experience people, even in virtual experience. And that's not what people need. At the end of the day, when I turn off my computer, I get to hug my husband, I know I get to hug my mom and my grandchild, I still had that which is so important to just being human. It's not just about having experiences. It's not just about doing different things. But the sheer isolation that results in loneliness, has such a profound impact on people who are perceived from the outside of people, as people who don't belong, it actually begins then to become something that happens and becomes ingrained inside of your own emotions and psyche that you don't belong. We can maintain hope and expectation that this pandemic is going to cease. And there will be some normalcy of life. People that I know who live with disabilities, there's very little hope that the shift will be so large, that it will remove the long experiences of isolation.

Raisa Habersham 11:49

That's heartbreaking. Like, I just, I'm speechless, because in my role, while I know it is to inform, there's a part of me that feels powerless. But also hope that through this, that I feel empowered to do a little more, speak up a little more, advocate a little more, on behalf of people with disabilities, the pandemic only further drove home the point that we're in a situation where we're being further isolated from society.

Derona King 12:23

And it's hard for us to imagine, because by definition, people who are segregated and isolated are not seen, right. This is part of the journey of uncovering and pulling back these layers, to expose something that's been right in front of our face our entire life, we would never accept it amongst ourselves. But for people with disability, that's the reality. That's the reality of a person who has maybe spent their formative years in a segregated special education classroom, in a school. They're separated from the general population, we all lose. Because just as you and I have gifts that our community benefits from, people with disabilities have gifts. And when people are segregated and isolated, for no reason other than their, their body may move differently, or their central nervous system may be operating differently for no other reason than those things, we miss out on their gifts.

Raisa Habersham 13:23

Where does this idea of protecting someone come from by further restricting them? I can't say that I've experienced that myself.

Derona King 13:34

Well, actually, you probably have experienced some, some of this kind of social protection, and it happens systemically. But it happens in micro ways, too. It happens in families in homes. I'm a mom of three kids. And it's very easy to begin thinking about, well, if I let you do X, Y, or Z, some harm will come. And everybody's mom or dad did that at some point. Right? But you without a disability, at some point, your mom said, Well, yeah, I guess you can drive, ride your bike down the street, yourself without me now, you're old enough. What happens for people with disabilities, this that that change doesn't happen, often within the system. So supposedly to safeguard someone or to protect them there are all of these rules and regulations and ideas about what should or couldn't happen for even an adult who has disabilities. This is deeply ingrained in culture. It's usually done not with ill intent, but it starts very early for people who have disabilities. And where the shift usually happens for young people without disabilities, it rarely happens for people who have labels.

Raisa Habersham 14:49

So this is where a citizen advocate comes in. As Derona explained to me by connecting people who have developmental disabilities, specifically with someone who shares a common interest, they'll develop lifelong friendships with people who feel like family. The concept reinforces the idea that people when given the right opportunity, or the cause, will represent and respond on a person's behalf as if it were their own family member. Derona has seen these relationships form in many ways, and has learned quite a lot from the relationships she's helped form.

Derona King 15:24

These matches are very personal and specific. There's something about truth, right? That gives you freedom, that when you allow yourself to connect with somebody who again, you perceive, that you know, culturally perceived as indifferent, when in fact, what do we need? We need people in our lives who know us well enough, that we can be vulnerable with one another. We can be with each other in good times and bad times that we can get it, we hold each other's backs and benefit from one another's gifts. That's the, that is literally my job to help people have those experiences. Just so happens one person is someone identified as having a disability. And the other person is someone who's identified as not.

So Derona, I'm going on this journey. And I want to know who should I meet first?

Oh, I have a great pair of people. Nasir and Garrick. They're, they're so engaging and their personalities play off of one another and you can almost feel the rapport in their conversations together. Garrick is a citizen advocate for Nazir, but really came—we kind of backed into Garrick being a citizen advocate. He and Nazir had a relationship prior to my even meeting Nazir. They had been involved together in some of the support that Garrick does around blindness and visual impairment. Garrick is blind, and Nazir is blind as well. And so, there had been a relationship, I think, just kind of in a paid way through, through Garrick's previous work and how he got to know Nazir. But the two just clicked it off so well that they became friends.

Raisa Habersham 17:09

Can you talk about how Nazir and Garrick's relationship exemplifies Citizen Advocacy's mission and values?

Derona King 17:18

Oh, thank you for that question. I really do think the relationship reflects the values of Citizen Advocacy. The work that we do, even though its protection and advocacy, is centered around this personal idea of personal relationship. Because here's the deal, we will all respond to, are more likely to respond to and protect people who we know about and care about. And that's really, really important for someone who has vulnerabilities in their life. If there's somebody in their life just because they want to be not that's it because they're paid to be the individual and personal connection and relationship means that it has a high likelihood that it can go on for a very long time. It has a really high likelihood of being a reciprocal relationship where Garrick isn't giving, giving, giving, but he's also receiving Nazir's gifts in return. The more that they are together, the more stories that they get to create, the broader their whole story becomes lifted up to the entire community.

Raisa Habersham 18:30

I love that I can't wait to speak with them both. I'm excited to hear their story.

Nazir Hardge has known Garrick Scott since he was 10. Both are visually impaired. they first met through a mentoring program at the Center for the Visually Impaired in downtown Atlanta. They bond over food, laughs and their love of women. Before the pandemic, they were on the verge of joining a baseball league. And like many of us are now navigating a new set of circumstances keeping them from the people and activities they love. Can each of you describe how the Covid 19 pandemic has kind of affected your relationship recently?

Garrick Scott 19:15

Nazir, you want to go first? Thank you. So we actually talk and occasionally Nazir will participate in pulling up facilitating for the youth, but I think sometimes he gets tired of seeing me. Back in January, Nazir started participating in a baseball league for the blind that I played in, and he actually joined our team, baseball league. And he was only able to come to one practice, but that was really going to be the start of us really having some activity that we do together that he and I both are on the same team, we both wear jerseys. And I think we were pretty excited about getting the chance to do that. Before, it was always something I was facilitating, and I invited him, but this was just something we were both doing equally.

Raisa Habersham 20:04

And so since then, have you all seen each other in person since the pandemic?

Nazir Hardge 20:09

No.

Raisa Habersham 20:11

And what's that like for you, Nazir?

Nazir Hardge 20:13

It's just, it's hard, it's hard to you know, even that kind of stuff is hard for me to, you know, not this evening, but I mean.

Garrick Scott 20:29

I think it calls me a lot more because he participated like a summer program that I did so we get to see each other. Technically we were on the same Zoom but it wasn't the same. So sometimes we eat a meal, but most times, we will talk on the phone but we talk much more regular, he calls much more regularly than before when we would occasionally see each other.

Raisa Habersham 20:53

Nazir, how important are those conversations for you with Garrick?

Nazir Hardge 21:00

It's kinda good. Very, kinda busy and all that kinda stuff. Like, I would be busy sometimes, and yeah, I just get crazy sometimes. And I have a lot of time, to call him

Raisa Habersham 21:19

Garrick says he and Nazir have a sibling-like relationship (although he jokes Nazir probably sees him more as an older uncle). The two joke a lot; they rag on each other about their looks and laugh at Nazir’s obsession with “Family Feud” and “Law & Order: SVU.” They also talk about women. Neither of them have a girlfriend, but they make their interests known. Garrick, do you two have conversations about women? And you know how to guide that?

Garrick Scott 21:48

Absolutely. So Nazir, if you’re out, if you’re out in public and there are a group of girls or a group of women, what’s something that you could say to the group?

Nazir Hardge 22:00

Hi, ladies. How are you?

Garrick Scott 22:02

There you go. There you go. There you go. We, we practice that sort of stuff all the time.

Raisa Habersham 22:09

And may I ask, why is that?

Garrick Scott 22:12

Society assumes more often than not that just because an individual has a disability, that one or two things, that one, if they find someone who wants to be with them, they have to be happy with whoever it is and whatever it is and however they’re treated, that that’s what they have to deal with; or two, they feel like they don’t have an interest in that sort of thing, that they don’t know about love or intimacy or physical contact, and so, there’s no need to have those discussions with them, when that’s extremely far from the truth.

Raisa Habersham 22:42

And Nazir, you know, you talked about you know, how you would greet a woman, you know, if you see her walking by or a group of women, if you see them walking by, you know, have you approached a woman beyond that?

Nazir Hardge 22:56

No.

Raisa Habersham 22:58

What's your comfort level with that?

Nazir Hardge 23:01

Um, I would say, I would say um-

Garrick Scott 23:10

Nazir, you remember, this is where we practice you're supposed to say I want to be just like Garrick when I grow up, remember that? You remember us doing that?

Nazir Hardge 23:18

You didn’t ask me to do that. I didn’t know that.

Garrick Scott 23:22

Oh, so sorry, sorry, sorry.

Raisa Habersham 23:29

Jokes aside, Garrick has been there for Nazir during some very tough times. Like when Nazir’s parents tried to claim guardianship over him when he turned 18.

Garrick Scott 23:39

So, the most difficult part is getting the family to understand that independence is going to look uniquely geared towards Nazir. So it won't be him necessarily hopping on a bus and going to a variety of places. And there may be some things that he just won't remember to do. But none of that negates his independence. And we have to allow him to determine what it looks like for him. But in doing so, we can't continue to just prompt, direct, order, facilitate everything for him. So like, even with this, even with this particular Zoom meeting, he called me and said, "Well, what time is the meeting? And when is she gonna call me?" And I said, "Nazir, I'm not answering any of those questions for you, 'cause when you had, on the phone, that was the information that you were supposed to ask, right? And he said "Yeah." I said, "So now, you might want to try to get in contact with her yourself and answer those questions so you can tell me." So, it's just a matter of not allowing him to become comfortable with everyone doing everything for him.

Raisa Habersham 24:49

I want to talk a little bit about, 'cause I know you've been in Nazir's life since he was 10. I know that when he was 18, his parents sought to have guardianship over him. Can you talk a little bit about that process and kind of how you worked to ensure that Nazir was a fully independent adult?

Garrick Scott 25:11

So, that was a bit stressful for me as an individual with a disability, 'cause I went through something similar myself when my family first realized that I too would be blind. And as much as things have changed in my family, I still hold on to that. So, I just felt like it was something very similar with Nazir. So, I really had to encourage his mom and give a whole lot of information to read, and just talk to other parents to understand that it's not necessary to have a guardianship over someone to still be a part of their circle of support and let them make a good decision. I think what happens is, most times, people want a person with disabilities to go through life perfect, and never make any mistake, when that's not the real world. We all make mistakes, and that's where we learn and we grow and gain wisdom. So that was the biggest process in the guardianship there. You don't have to have legal papers to control someone's life in order to help them.

Raisa Habersham 26:19

Nazir, when your parents did try and get guardianship over you, how did that make you feel?

Nazir Hardge 26:26

It did make me feel kinda nervous and... nervous and anxious and all that kind of stuff.

Raisa Habersham 26:43

How do you feel now knowing that you know you are independent and that you you're not on guardianship?

Nazir Hardge 26:51

I feel okay, doing it this way. But I'm doing this for myself is just coming to seem easy and kinda easy to do it and all that kinda stuff.

Raisa Habersham 27:19

I couldn't stop thinking about how Garrick and Nazir have to navigate dating. I realized I never had to worry about being misunderstood as someone who can't develop strong feelings, or worse, who doesn't understand the concept of love. I had to tell Derona about how I felt. Initially when you know we got in the concept of dating and Garrick mentioned, you know how he talks to Nazir about how to greet women, my first thought as a woman was okay, he's telling him not to cat call and how to treat them with respect. But when I asked him, you know why they, you know, talk about that it was different. It was because he said people tend to assume that people with disabilities don't have those feelings, don't share those feelings. Don't think about that. And that's not the case. The dynamic, obviously, in my experience, as a woman walking down the street, versus they're experience as people with disabilities walking down the street is different. And that was immediately clear when he said that, and it just was eye opening because I was like wow I never thought of it that way.

Derona King 28:33

That's another one of those kind of wounding life experiences, that's associated with people who are are labeled with disabilities, there's almost by the wider culture, this perversion in either direction, either a person would be asexual, like no interest at all, or hyper sexual and get some of that deviancy attached to that. And none of those things are true. We all need the same thing. Like one of the most powerful needs for the human soul is intimacy, personal relationship, and love. If you're always told even unspoken, no, you can't or you shouldn't, no, you can't or you shouldn't. And you've got to, if you're going to have a girlfriend, she's gonna have to be another girl, somebody with a disability like you. And those are the things that people with disabilities are often faced with. That's a really big part of where they are as kind of this role. You know, this uncle and it's a very natural thing, right has a young, how is he going to know about sexual relationship, love, and intimacy. His family's not modeling that for him, right? You know, because they want to treat him like a six year old and keep them close. And these guys get to go out and navigate that. They get to figure it out together. And I think the experience across the board for Garrick as a citizen advocate is the invitation is, how can you help Nazir to have more inclusive life experiences when we talk about what's the typical experience for nausea, it shouldn't be just the people in from a special education class or the whatever day program other people with disabilities or go to this disability event organization. Not that it's not, that can't happen, it's a starting point. But bigger, more expansive life will circle back to being able to meet different people, right, to form those relationships, figure out how other people you know, it's certainly getting a job, people meet people on their jobs, real jobs. And it's all connected. The more expansive, the fuller we can support people, the better opportunities, they have to think creatively about what life can be. And that's, again, part of the interdependence of adulthood.

Raisa Habersham 30:51

Yeah, I mean, it's very layered. But you're very rarely taught, say, disability studies.

Derona King 30:57

Our culture, the American culture particularly, is not conducive to even seeing people with disability in community, like just seeing people. I had a friend who was a woman who was from Toronto, and she is a woman who experienced cerebral palsy, used a wheelchair needed support, some communication support, just a wee bit. I remember her, Judith was her name. And she was a pretty powerful influence not just on me, but on probably the world, in terms of how to think about disability. Judith would say, "I didn't have a disability until I crossed the border into the United States." So it's about attitudes and assumptions. It's about what what we perceive as different. In Toronto, Judith lived her life, just doing all the things. She gets to America, across the border, and there is a whole new set of assumptions and expectations around who she was, because people saw a person in a wheelchair.

Raisa Habersham 31:59

It feels like we almost intentionally dehumanize people in the States.

Derona King 32:05

What we hope to continue to do through the work of Citizen Advocacy is bringing a few people together in personal relationship. How do I extend myself in real life to my friends? Well, here's a person who has a friend now who happens to have a disability. And as much as Nazir has benefited from being in a relationship with Garrick, Garrick has benefited from being in a relationship with Nazir. The reciprocity of relationship is what we hold up. And I think you could hear that in terms of asking the question about love and friendship and being together, and even just their interactions with one another. And that's what people need.

Raisa Habersham 32:51

I think I have a lot to process around the concept of love. It will take a lot of, for me, unlearning things that either I've seen or held strong to and believed.

Derona King 33:03

Raisa, I have some people for you to meet. There are some pretty amazing stories out there. And I'm really excited for us to be able to dive into here and more of these.

Raisa Habersham 33:18

Join us for the next episode of Hidden Voices, where we’ll talk about love, dating and starting a family during a pandemic.

This podcast is a collaboration between the Georgia Council on Developmental Disabilities, Resurgens Impact Consulting, Citizen Advocacy of Atlanta and Dekalb and L’arche Atlanta made in partnership with FRQNCY Media. I’m your host, Raisa Habersham and Derona King is my co-host. Our Executive Producers are Irene Turner from The Storytelling Project and Michelle Khouri from FRQNCY Media. Enna Garkusha is our Producer. Matthew Filler is our Editor. Hidden Voices is sponsored by the Georgia Council on Developmental Disabilities. This vision is a state in which all persons are included in all facets of community life, have choices while exercising control over their lives and are encouraged to achieve their full potential. GCDD advances social and policy changes that further and integrated community life for persons with developmental disabilities, their families, friends, neighbors and all who support them. This podcast grew out of their larger GCDD Storytelling Project. You can find out more about them and their great advocacy work for and about people with developmental disabilities at GCDD.org.

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